



The Working Group to Develop a State Plan for Alzheimer's Disease and Related Disorders

Full Group Meeting

September 18, 2012
10:30 – 12:00 pm
Casey Family Services
1268 Eddy Street
Providence, RI 02905

Kathy Mckeon
Peter Snyder
Donna Desmarais
Maria Barros
Faith Sands
Jennifer Wood
Tsewang Gyurmey
Tom Kane
Maureen Maigret
Susan Saccoccia Olson
Andrew Powers
Edward Stopa
Karen Proffitt
Marge Angilly

Cynthia Conant-Arp
Catherine Taylor (Chair, DEA)
Lt. Gov. Elizabeth Roberts (Chair)
Pat Chace
Gail Patry
Janice DeFrances
Rory Carmody
Ana Tuya Fulton
Lola Okunfolany
Stacey Paterno
Kathy Heren
Valerie Topp
Lori Daiello

1. Call to Order

- The Chair called the meeting to order at 10:35 am.
- The Lieutenant Governor welcomed everyone and thanked them for coming. She turned it over to Catherine Taylor for a brief update on her trip to the National HCBS Conference.
- Director Taylor informed the group that she had attended the Home and Community Based Services Conference recently.

- Attended sessions from Administration of Aging - Involved in writing of National plan on Alzheimer's Disease.

2. **Overview of National Plan on Alzheimer's by Dr. Peter Snyder**

- The Act: Create a national strategic plan to find a successful treatment and create a gap analysis to identify better care for older adults.
- Advisory Council: Standing committee that will annually revise the plan. During the first year of implementation, Council will create a list of needs that will facilitate completion of gap analysis. In subsequent years, the Council will focus more specifically on details of identified issues and challenges. The Plan will be annually submitted to Congress, who will make recommendations on research monies, investments, and priorities.
- Goals: Prevent and treat Alzheimers & enhance quality and efficiency of care. Additionally, to expand services for people with Alzheimer's and their families, including but not limited to, connecting individuals with the necessities, enhancing public engagement, entering consenting families in clinical trials, enhancing trust between patients/caregivers with researchers/Pharmaceutical companies. Finally, track progress to ensure that goals are met and revised as needed.
- Appendices: Maintain inventory of research and programs by topic area to clarify what we have and indicate what areas we need to supplement.
- Immediate Actions: NIH will dedicate an additional \$50 million for research (mainly genetics) and \$80 million more in the next year.
 - In Rhode Island, a multi-institutional study is being done (approximately 200 patients and \$15 million budget). There is great interest in developing new longitudinal studies, however, would need funding. Possibly use course for patients as the primary endpoint rather than the outcome of a longer clinical trial.
 - \$26 million included in National Plan for Education, Outreach, and Community support efforts.
- Strategies: Increase enrollment in clinical trials and clinical research through community, national and international research.
 - Look into implementation of lifestyle changes and preventative steps (eg. exercise, fish oil pills).
- National Plan vs. State Plan: Ideally, State plan will not mirror National plan, but compliment it.
 - National plan is to be used as a template, with the same imperatives, but with possibly different priorities that are impacted by state needs. The State Plan should ddresses generic goals, but drill down to concrete operational steps.
 - Additionally, we should take into consideration federal resources, but also consider state resources to meet RI's goals.

3. **The Lieutenant Governor Lead a Discussion of the State Plan:**

- State Imperatives In Plan
 - Legal Concerns are largely state jurisdiction and are not included in the National Plan
 - Legal concerns should be forthcoming in the national plan. Other state laws are more likely to err on the side of caution and not necessarily on what works.
 - K. Heren: We need to address issue relating to hospice care and helping people adjust using the care setting. Long stay hospital patients -- If individual is without family, they lack resources and tools to get them into a better situation
 - J. DeFrancis: Interested in looking at best practices (prevention and intervention) as the inventory comes together
 - Is there a way to include an assessment of quality and outcomes. Will inventory include a description of Pros and cons of settings and providers?
 - Age limitations were also mentioned: Younger onset Dementia population is growing and falling through the cracks.
 - C. Conant-Arp: Importance of access, particularly financial, to quality care. Finances are a huge barrier without Medicaid. This is a huge issue for individuals with early-onset Dementia. National Plan doesn't address quality of life for those who currently have Alzheimer's.
 - K. Heren: Differences in access between Medicare and Medicaid patients is an important topic to consider.
 - Importance of Education around resources and education for people who have to make medical decisions for their parents, too.
 - Dr. Snyder: Focus on keeping individuals in their homes, which is most desirable and least expensive. National commitment to research has been very lackluster.
 - M. Maigret: Coordination of primary and specialty care; educating physicians on how to diagnose and screen in primary care setting. Also, interest in addressing the needs of individuals who live at home alone.
 - The tension between staying home and receiving appropriate medical care is essential.
 - C. Conant-Arp: Senior housing directors deal with the challenges that are addressed in the above point. We need to keep them in mind and involve them.
 - S. Paterno: Patients in their homes are unable to access guardianship type programs because they do not come from institutional settings and are first identified in a hospital.
 - All or nothing approach: Choicer are primarily nursing home/hospital or home, which ignores adult day care and other similar services.

- Dr. Snyder: What is the burden on the family when access to nursing homes/assisted living is more difficult. Family caregiver needs are a big problem, especially for individuals with early dementia and later stages with impairments.
- The need for professionalization of the role of home care workers and community care workers was also mentioned.
- Home Care Companies: Medicaid can get home care covered, but some are stuck in the middle and cannot afford these services. These families need something in place to help them ease the burden of caring for their family members (money).
- M. Barros: Family burnout can lead to abuse and neglect. Medicare does not cover ongoing home services and many patients do not qualify for state services. Families lack support and education, but Alzheimer's Association cannot help everyone
- DEA Co-Pay program helps people just above Medicaid Level, Could possibly be expanded, as it is an important transition.
- Problems will arise if elders aren't receptive to home care. We cannot rely solely on this option.
- Adult children need education to assist their parents in getting the care they require.
- Need for creative ways of integrating community education and involvement and working group's mission.
- C. Taylor: Issue of family support/respite for individuals caring for a family member with a disability. There is a need for this, and a lack of a coordinated effort.
 - Large Elderly population and early retirees who would want part-time work. Workforce issues could develop in-between supports for this population.
- Integrate Housing: Senior housing that offers preventive and other services.
- Research: Think outside of national money in efforts to integrate RI work with initiatives that are taking place in homes and agencies.

The Meeting was adjourned.